From: "Collins, Francis (NHGRI)" <francisc@exchange.nih.gov>
To: "Varmus, Harold" <hv2b@nih.gov>
Subject: FW: Public-Private Collaboration on Human Genome Sequencing
Date: Fri, 5 Feb 1999 21:12:19 -0500
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Harold, in case you have a chance to look at it before we talk tomorrow, here is what we sent to Rachel Levinson yesterday in response to the Podesta inquiry. I am still unable to determine the origins of the White House concern on the issue of the MOU.

Francis

-----Original Message-----
From: Hudson, Kathy (NHGRI)
Sent: Thursday, February 04, 1999 4:37 PM
To: 'rachel'
Cc: Hudson, Kathy (NHGRI); Collins, Francis (NHGRI); Jordan, Elke (NHGRI); Guyer, Mark (NHGRI); Higgins, Craig (NHGRI)
Subject: Public-Private Collaboration on Human Genome Sequencing

Rachel-

Following is some information in response to your question today about the current status of public-private collaboration of human genome. I will fax you the press announcement on the fly mou. Call if you have questions.

* In FY1999, the international Human Genome Project will spend $194 M on human genome sequencing (NHGRI-$110M, DOE-$34M, Wellcome Trust (UK) estimated $50M)
* In 1998 two initiatives to undertake large-scale human sequencing were announced by private sector companies. While most private sector efforts to sequence all, or part, of the human genome plan to retain the information for proprietary purposes, Celera Genomics has stated it intends to release the sequence data publicly on a quarterly basis. In addition, Celera Genomics has stated that they intend to complete their whole genome shotgun version of the human sequence by 2001, two years ahead of the schedule for the publicly supported Human Genome Project to produce a final completed sequence. As a result, questions about federal support of human sequencing have been raised. The international Human Genome Project is fulfilling its promise as the single most important research effort in biology and the biomedical sciences. Providing a complete, high-quality sequence of human DNA to the research community as a publicly available resource continues to be the Project's central priority.
* Initial support for the Project was primarily provided by public and not-for-profit sources. More recently, private, for-profit organizations have made important contributions toward achieving the goals of the Human Genome

Project and applying genomic information toward the improvement of human health and well being. Accordingly, there is great opportunity for cooperation between the public and private sectors to expedite meeting the Project's goals.

* At the same time, it is well recognized that there exist genuine and important differences in research approach and objectives between the parties. However, these differences should not prevent cooperation in many areas, as everyone recognizes and acknowledges the importance of delivering the complete and accurate sequence of the human genome to the broad scientific community as soon as possible.
* The NIH welcomes the strong interest in genomics evidenced by the developments in the private sector over the last year. This interest testifies to the tremendous value of the research tools being developed by the Human Genome Project and being put to use by disease investigators in both the public and private sectors.
* The NIH is actively seeking opportunities for collaboration with private sector entities engaged in large-scale human genomic sequencing. In particular, the NIH is discussing means of collaboration with the one company, Celera Genomics that has announced its intent to sequence the human genome and deposit the sequence data into GenBank, the publicly available genomic database maintained by the National Center for Biotechnology Information at the National Library of Medicine at the NIH.
* Because of the differences in sequencing strategies utilized by the public sector and Celera Genomics, there may be opportunities for forging an effective collaboration that enable both the public and private sector programs to meet their goals more expeditiously and more affordably.
* Public-private collaboration moved forward on January 19, 1999 with the signing of a memorandum of understanding between Celera Genomics and the Berkeley Drosophila Genome Project Group. The MOU's stated purpose is to produce a "complete, annotated, and publicly accessible sequence of the Drosophila genome at reduced costs and at an accelerated pace." The Berkeley Drosophila Genome Project Group is a consortium of research groups working at the University of California at Berkeley, Lawrence Berkeley National Laboratory, Baylor College of Medicine and Carnegie Institution of Washington. The group is funded by the NIH, the Department of Energy and the Howard Hughes Medical Institute.
* Intensive discussions are now underway between NIH, DOE, and the Wellcome Trust concerning terms of a possible MOU between the publicly supported Human Genome Project and private companies in the area of human sequencing. Agreement among these parties is critical to sustain inter-agency and international collaboration and cooperation on the Human Genome Project.
* Initial drafts of the MOU, if adopted, would have caused irreparable harm to the Human Genome Project. Time invested now to work these problems out will save time and money later. While the public sequencing efforts continue at an ever increasing pace, to our knowledge, Celera is not yet producing human genomic sequence. Thus, there are no costs to time invested now to develop a thoughtful MOU.
* Recent media reports suggest that federal agencies have slowed progress on development of an MOU. These reports are misleading, if not inaccurate.

Careful, deliberate consideration of all elements of the MOU is essential to protect the public investment and sustain the collaborative spirit of the Genome Project.

* Once the U.S. Human Genome Project and international partners at the Wellcome Trust develop a set of agreeable terms, discussions with individual companies can be initiated.

* However, since public and private sectors have somewhat differing goals, tensions may arise during these discussions. The publicly funded effort is committed to placing all sequence data in the public domain, with no patents, as quickly as possible. By necessity, however, private efforts must seek to recoup their financial investment by filing patent claims and/or restricting access to the information.

* Therefore, critical to the success of any collaboration is NIH's commitment to maintain the high standards for human sequencing and the full public accessibility of data established by the NIH-DOE and our international partners and embraced in the Project's new 5-year plan.

1) The sequence must be accurate. An accuracy of 99.99 percent or better is the current goal;

2) The sequence must be assembled into long contiguous pieces that reflect the original genomic DNA.

3) The human DNA sequence must be publicly accessible and available to the entire research community. The public project has committed to the release of genomic sequence data of at least 1-2kb in length within 24 hours.